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The impact of spine sarcoma on mental health and wellbeing

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Spinal sarcomas are rare and often extremely debilitating, cases may involve multiple vertebrae, epidural space with spinal cord compression, adjacent solid organs and the paraspinal musculature [1]. Treatment is taxing, potentially requiring a multimodal approach involving surgery as well as radiation and/or chemotherapy, and there is a relatively high rate of disease recurrence [1,2]. Surgical treatment of spine sarcoma usually requires a complete resection without physical breach of the tumor capsule to gain maximal local tumor control [3,4]. To achieve this the planned surgical morbidity might be very high, including functional nerve root ligation. Despite this, the tumor may return locally or with metastasis. Given its rarity, delays in diagnosis of spinal sarcoma are not uncommon and can lead to considerably poorer outcomes [5]. This includes, but is not limited to, spinal cord injury, nerve root damage/sacrifice and poorer prognosis [6].

Arguably, a further layer of complexity is added when the psychological implications of spinal sarcoma are considered. When a traumatic experience, such as cancer, occurs, it is critical to take account of the social, emotional and contextual factors that may influence adaptation. However, despite the debilitating effects of spine sarcoma, the experiences of and challenges faced by patients with spine sarcoma and their families has received limited research attention to date. We will discuss the individual and contextual factors associated with wellbeing following trauma and how these could relate to adults and children with spinal sarcoma. The present review of the potential psychological impact of spine sarcoma is particularly timely given the release in the United Kingdom (UK) of the NHS' Long Term

Plan, highlighting the urgent priority of mental health support. This was also identified as the fifth most important area for research in the James Lind Alliance priority setting exercise for patients living with and beyond cancer (<https://www.ncri.org.uk/lwbc/>).

Individual factors

Many individuals with various forms of cancer can find the experience of diagnosis and treatment to be challenging and traumatic [7]. For example, the need for invasive procedures, intensive treatments, hospital stays and separation from the normal aspects of daily life have been found to be highly stressful and may have a significant impact on a patient's psychological adjustment [8–10]. Previous studies have found that children report a range of stressors relating to their cancer diagnosis and treatment, including the physical side effects (e.g. fatigue, nausea, pain from the disease/treatment), anxiety (e.g. concerns about treatment, death) and social concerns (e.g. lack of social support, home sickness, and changes in appearance following treatment)[9,10]. Such concerns may be especially applicable to patients with spinal sarcoma, particularly as the required treatment can call for long hospital stays, prolonged isolation from friends, and entails significant changes to one's appearance or mobility, loss of sexual function and continence. Nonetheless, although treatment is often invasive and laced with uncertainty about disease relapse, how patients perceive and experience their diagnosis/treatment in cases of spinal sarcoma remains under-explored.

Unsurprisingly, a proportion of patients with cancer will meet criteria for mental health difficulties, such as post-traumatic stress disorder (PTSD), major depression, and anxiety disorders [11–13]. Such psychological problems are highly comorbid and are associated with poorer quality of life, maladaptive coping, and substantial distress (Williamson & Greenberg, in press). It is likely that the nature of a spinal sarcoma diagnosis and treatment may cause considerable distress. International research efforts are currently

underway to detail markers of physical wellbeing in cases of spinal sarcoma pre- and post-treatment (<https://aospine.aofoundation.org>); yet no data about the mental health or the proportion of patients referred for formal psychological support are available (Storey et al., under review).

Contextual factors

Social support has been found to be a key protective factor against psychological problems following a range of traumatic experiences [14]. How patients with spinal sarcoma experience social support following diagnosis and treatment and their ongoing support needs remain poorly understood. Supportive responses, including high levels of family cohesion and communication, have been found to be helpful in cases of other cancers [15]. Familial support may be particularly relevant for children and young people with cancer as parents and siblings are likely to be their primary source of psychological support, especially in cases where the child is too ill to attend school or socialize with friends. However, other parental responses, such as overprotection, have been found to be associated with poorer child outcomes post-trauma [16]. Such maladaptive parental responses can stem from parent appraisals that the world is unsafe, that the child is vulnerable [17] and have been found to occur when parents perceive that their child received poor medical care [18]. Whether these responses impact adjustment following spinal sarcoma requires further investigation.

The process of cancer diagnosis and treatment can be profoundly distressing for both the patient as well as their family members. Experiences of cancer can significantly disrupt family routines and family functioning, cause financial difficulties (e.g. caregiver taking time off work, payment for treatment), and put strain on marital relationships [15]. Treatment for spinal sarcoma can be very challenging to access as there are few dedicated spinal sarcoma centres globally. For example, only four centres exist in the UK, meaning that patients

frequently have to travel long distances for care. This may add an additional financial burden to an already challenging time for many patients [19]. From a healthcare provider perspective, it can also be difficult to counsel and consent patients regarding risks and benefits of treatment. Ensuring patients understand the potential risks and implications of treatment is an essential part of managing illness uncertainty, defined as a sense of loss of control which is linked to maladaptive coping, higher psychological distress, poorer responses to pain, and reduced quality of life [20]. Furthermore, significantly high levels of major depression, anxiety, and PTSD have been found in the family members of individuals with cancer. For example, some studies find that the spouse or the parent of an individual with cancer is more distressed than the patient themselves [7,21,22]. In light of the pernicious effects of the disease and aggressive nature of treatment, it is possible that the families of patients with spinal sarcoma are especially vulnerable to experiencing psychological distress.

Directions for future research

The evidence reviewed suggests that spinal sarcoma may have a deleterious effect on the psychological wellbeing of patients. Given the known adverse impact of cancer on adaptive functioning, future research is needed to explore the effects of spinal sarcoma diagnosis and treatment, and patient/caregiver formal support needs. Epidemiological research to determine the incidence and prevalence of psychological problems in patients with spinal sarcoma compared to patients with other cancers and the factors associated with poorer mental health outcomes may also be beneficial. As differences in the process of accessing care and receiving treatment vary by context (e.g. US, UK, Canada, etc.), an investigation of nation-specific risk factors for mental health problems in spinal sarcoma cases may be needed. Longitudinal studies would be helpful in determining how risk and protective factors influence adaptation over time.

96 The importance of caring for patient wellbeing as a whole, encompassing both mental
97 and physical health, has been highlighted in previous studies across a range of disorders [23].
98 Nonetheless, the provision of care in the immediate aftermath of spinal sarcoma diagnoses is
99 focused on physical versus psychological well-being. Ensuring appropriate guidance and
100 support is available in cases of spinal sarcoma is likely to be central to fostering wellbeing
101 and quality of life. Currently, an investigation of the support needs of patients with spinal
102 sarcoma remains outstanding.

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